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What matters to users of services? An explorative study to promote shared decision making in health care

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Abstract

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Background Involving service users and carers in decisions about their health care is a key feature of health-care practice. Professional health and social care students need to develop skills and attributes to best enable this to happen.

Aims The aims were to explore service user and carer perceptions of behaviours, attributes and context required to enable shared decision making; to compare these perceptions to those of students and academic staff with a view to utilizing the findings to inform the development of student assessment tools.

Methods A mixed methods approach was used including action learning groups (ALG) and an iterative process alongside a modified Delphi survey.

Participants The ALGs were from an existing service user and carer network. The survey was sent to sixty students, sixty academics and 30 service users from 16 different professional disciplines, spanning four Universities in England.

Results The collaborative enquiry process and survey identified general agreement that being open and honest, listening, showing respect, giving time and being up to date were important. The qualitative findings identified that individual interpretation was a key factor. An unexpected result was an insight into possible insecurities of students.

Conclusions The findings indicate that distilling rich qualitative information into a format for student assessment tools could be problematic as the individual context could be lost, it is therefore proposed that the information could be better used as a learning rather than assessment tool. Several of those involved identified how they valued the process and found it beneficial.

Introduction

This article gives an overview of a project conducted to inform the development of assessment tools for use in practice placements for a range of health and social care courses in four Universities in the UK. There is a growing body of work involving service users and carers in the design and conduct of student assessments. The majority of this work has focused upon single disciplines or areas of practice, for example, mental health^{1–5} social work^{6–8} and podiatry.⁹ Rather than identifying a specific clinical area or professional group, this study focused upon a skill considered important to them all. The particular focus was an exploration of the factors considered important for the promotion of shared decision making and partnership working between professionals and service users and carers.

Background

During the last two decades, government initiatives to modernize health and social services have driven a cultural change aimed at delivering a genuinely patient-centred approach to care.¹⁰ Fragstein *et al.*¹¹ refer to patient-centredness as a key feature of high quality of care. There has been widespread acknowledgement of the need to involve patients and the public in all aspects of health care^{12–14} and current policy sets out the statutory requirements in the Health and Social Care Act, 2001. The Department of Health produced a draft framework for creating a stronger local voice in the development of health and social care services.¹⁵ Much of this work focused upon the support and organizational processes needed to ensure effective involvement in the commissioning, provision and regulation of health and social services.¹⁵ This involvement is not limited to one type of service or professional group, it is characteristic of them all. Students entering any of these services therefore need to be able to work in a way which helps to enable service users to fully participate.

The noticeable culture change within the past decade is also affording new opportunities for

service users and carers to influence practice through involvement in the education of professional health and social care workers. Significant developments have been made in relation to partnership working between service users, carers and universities especially in relation to involvement in the teaching and learning process in the classroom, for example, Simons *et al.*¹⁶ Some regions developed principles for service user involvement in healthcare educational practice¹⁷ and user voices have already defined the standards expected for appropriate involvement.¹⁸

Practice placements provide an ideal setting for service users and carers to be actively involved in the learning experience of the student, including participating in the assessment of 'fitness to practice' as required by professional, statutory and regulatory bodies, for example, the Nursing and Midwifery Council. User and carer involvement should be supported by a systematic process that includes involvement from the initial stages, from the identification of common competences for practice, to formulation of an assessment tool and ultimately participation in the assessment process. Recent work has included the involvement of service users in the process of assessment of students' clinical competence.^{2,4,5,7–9} A general finding from these studies is that involvement is important but that further work needs to be undertaken to understand the complex factors impacting on the process. Stickley *et al.*² conclude that a process of feedback to support learning is more appropriate than direct involvement in summative assessments.

What is perhaps less well established is partnership working in relation to the development of assessment tools which could be used during placements. This study has supported leading efforts nationally to apply learning from involvement in educational change,¹⁹ PEPIN network <http://pepin-uk.net/>).

The four universities (Bradford, Huddersfield, Leeds and Leeds Metropolitan) involved in this collaborative work were all part of a wider project the Assessment and Learning in Practice Settings Programme (ALPS). ALPS is a

collaborative programme between five Higher Education Institutions: those just stated and York St John with the aim to ensure that students graduating from courses in health and social care are fully equipped to perform confidently and competently at the start of their professional careers so improving standards of care (<http://www.alps-cetl.ac.uk>).

A fundamental part of ALPS is the creation of generic assessment tools that are mapped to three identified common competences, communication, teamwork and ethical practice. The assessment tools can be used for self assessment, inter-professional, peer and practice assessment and service user and carer assessment. ALPS funded this research project through the research capacity funding with a view to advancing the goals of ALPS specifically in relation to service user and carer involvement.

The four universities (Bradford, Huddersfield, Leeds and Leeds Metropolitan) had an existing collaboration and had undertaken work supported by the Yorkshire and the Humber Strategic Health Authority. Integral to this work was the widening participation initiative at the University of Leeds School of Medicine that encourages individuals with long-term conditions and carers to become involved in the delivery of health professional education. From this initial work, a 'Patient Learning Journey (PLJ)' programme²⁰ was established across West Yorkshire, from which the service users and carers involved in this study were identified.

Learning from this collaboration enabled us to identify what helps meaningful, as opposed to token contribution by the public. The key is recognition of the value of the capacities of users and carers, rather than an emphasis on their deficits and needs, and of their role as co-producers in health. It was considered important to apply the same enabling processes that support the necessary transformation of relationships in health and social care^{21–23} to the conduct of the study.

There was a recognized need to build upon local work that has contributed to international understanding of the growing field of public

involvement in professional learning.²⁴ In particular, a project was required that employed methods of involving users and carers in developing re-usable learning materials in e-learning approaches as developed at Bradford University.^{25,26}

Working extensively with users and carers both across universities and in our own departments led the project group to think more outside our professional silos and we had a 'back to basics' urge to involve service users and carers in re-thinking professional worker and service user interactions. We were advocates for the service user contribution to all aspects of curricula and aware of its possibilities and the barriers to achieving these.

There were 10 people on the project group with representation from each of the Universities including a service user, service user and care involvement workers and academic staff.

Aims and objectives

The aims of this project were to build on and deepen important learning about the capacities of service users and carers to take a fuller part in care, to understand more about how this can be enhanced by professionals and in student learning and to support the ongoing development of users' and carers' contribution to professional learning. Our objectives were:

1. To establish a collaborative inquiry process with action learning groups (ALG) to explore user and carer understanding and perceptions of the behaviours, attributes and context that health and social care students require for effective communication, shared decision making and partnership working with users and carers.
2. To conduct a modified Delphi inquiry with users and carers from the PLJs programmes, students and academic teachers to identify if there was a consensus about the identified attributes.
3. To inform the design of assessment tools for the core common competencies of the ALPS project.

4. To provide a reference group for validation and co-creation of assessment methods for current and developing teaching (e.g. Observed Structured Clinical Examinations, scenarios for simulated patients, reflective portfolios).
5. To produce materials that would have the potential to be used for re-usable learning objects.

These objectives contributed to the ALPS agenda, furthered the existing work of the collaborative group and would hopefully contribute to the wider literature on service user involvement in health and social care professional education. To do this effectively, users and carers needed to be supported to become our educational and research partners.²⁷

Methodology

To help to enhance the capacity of service users to contribute to the study, we needed to mirror how professionals can enable user contribution to care and decision making. We therefore chose research processes that are reflexive and participatory,²⁸ that allow for exploration of the complexities of roles and relationships in modern healthcare²⁹ and attempt to model the transformation of relationships needed.³⁰ We decided to work first with service users and carers in an action research mode with collaborative, focus groups (referred to as ALGs) where those conducting the groups actively contributed to the discussions. This formed part 1 of the study. The findings from the ALGs were then used to construct the survey questionnaire for part 2 of the study.

The survey was to determine if there was a consensus with the findings from the ALGs between other service users, students on health and social care professional preparation courses and academic staff from the same courses. A modified Delphi technique was used for this process. The Delphi survey technique is a research method originally designed for forecasting and has been used by policy

makers since the 1950s.³¹ It has been used to determine service user preferences.^{32,33} It is a consensus method which can enhance decision making in health and social care by transforming opinion into group consensus.³⁴ This is carried out through an iterative, multistage process that refines opinion data. Opinions are initially drawn from a group of experts; in this study, the experts are the service users and carers.

The project group kept in regular communication via emails and meetings whilst different individuals took responsibility for leading specific tasks.

Ethics

Ethical approval was obtained from all four Universities involved in the research. Informed consent was obtained prior to participation in the study and importantly further consent was obtained from service users and carers to include their comments in reusable learning objects. Permission was also obtained from the ALGs to edit excerpts from the audio recordings of their discussions for learning materials.

The aims and objectives of the study were addressed within two distinct parts, a collaborative group inquiry (Part 1) followed by a modified Delphi Survey (Part 2).

Part 1: a collaborative group inquiry

Participants. A diverse group of users and carers who had been through the 'PLJ' programme were invited to participate. The programme involves users and carers sharing their experiences in health and social care, evaluating what could have been performed by the professionals, and also by themselves, to improve relationships and outcomes.²⁰ From this participants consider how to translate their experience into useful learning points for students.

As all of these people had participated in the same programme, they had worked through a process of considering how their healthcare experience could be used to

enhance the education of health and social care staff. Some of the group were also known to each other. They now met as the ALGs in three separate groups of five or six to further examine their experiences of involvement in decisions and partnership working in the practice setting. The specific focus was to consider how students and professionals can enable them to play *their* part in shared care and decision making.

Data collection. The ALGs were facilitated by two university user and carer involvement workers, one of whom was the lead facilitator for the PLJ programme. After each session, the facilitators reflected on the discussions, aided by listening to the audio recordings, made notes of emerging themes and then met again before the next ALG to review their notes. The data collection within the session was conducted as an iterative process, building upon previous notes and reflections.

The facilitators were supported by an academic communication specialist who encouraged the facilitators to interrogate the data in the light of their own experience as service users and as facilitators, and guided to consider the theoretical context of their preliminary findings. The academic also observed the first ALG. The meetings with the second and third action groups were refined as a result of these reflections. The cumulative reflections were circulated to the project team for comment and revisited in project team meetings. All participants from the three action learning groups also received the notes of the meetings for further reflection and comment.

An initial framework developed during the reflective meetings was presented at a meeting of all three of the ALGs for comment and discussion about the way forward. The project lead for this stage also attended the meeting along with the project lead for the modified Delphi Survey (Part 2).

Through this process of small and larger group discussions, reflection and email communication, the ALGs identified what they considered as important criteria for assessing

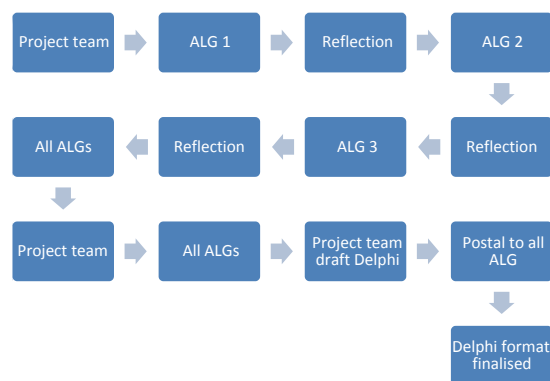


Figure 1 Overview of stage 1. Flow chart demonstrating the stages of the research process. ALG, Action Learning Group.

students' capacity to support them in shared care and decision making (Fig. 1).

Findings. The initial framework for bringing together the work of the different ALGs was drawn up during the reflective meetings between the two facilitators and the academic lead for Part 1. Four categories were proposed: Attention, Environment, Knowledge Diversity and Attitude.

Attention: this included to self, the other and the relationship including demonstration of respect.

Environment: this included the environment of the encounter, supporting the use of resources and dealing with people within the context of their lives and communities.

Knowledge diversity: this included communications skills, being clinically up to date and flexibility.

Attitude: this included being open, non-judgemental, self reflective and honesty.

This was used during the large workshop that brought together the three ALGs to share and re-examine their findings. However, the group found it difficult to work within the categories preferring to organize statements under the following headings.

Respect and Person-Centred:

The nurse listened and understood where I was coming from. She looked at things from my point of view – I needed someone to listen to me and hear what I was saying, to find a solution – she really wanted to help.

Knowledge and Power:

As his carer I know more things about him than they do.

Both doctor and patient are experts and should work together

Time:

Too much pressure on staff, they are not allowed to care due to time restrictions – high stress levels eventually makes them bail out.

Communication:

Speak at our level but don't assume our level.

I really want to know you're listening.

Team working:

Communicate with other professional's to smooth our way in getting help.

The Organization:

OT was very young and open-minded – not worried about ticking boxes and just pleasing management – no doubt this will have to change.

The Relationship:

The consultant was very apologetic and he admitted that 'Your mother knows best' so I have great respect for him.

I came out lighter because he's listened to me and lightened the load.

What became apparent throughout this process that attempting to identify and list the behaviours and attributes considered important for enhancing shared decision making was problematic. There was a fear that taking a statement out of context could lead to misinterpretations. For example, one person felt that it was important to see the behaviour of hand washing as they felt that this demonstrated the attribute of respect. In trying to combine the different perspectives, the final survey questionnaire agreed via this process contained a list of six attributes and five behaviours which could be rank ordered along with a range of agree/disagree questions. The construction of the questionnaire to be used for the 'modified Delphi inquiry'

is where part 1 and part 2 of the study overlapped.

Part 2: a modified Delphi inquiry

The number of stages taken in a Delphi survey is arbitrary but generally the more iteration, the more robust the consensus. Turoff and Linstone³⁵ warn of the pitfalls of either over- or under-refining the original data, both of which can reduce the original intention of the 'experts'. In this study, the amount of iteration seemed appropriate in both achieving consensus on the questionnaire content and in staying true to the original opinions expressed.

In using a Delphi survey to confirm the expert opinion, rather than to forecast an event or trend, this study has veered away from the true purpose of the Delphi approach and as such a modified Delphi has been used. A modified Delphi has been used successfully for other studies, for example, Ricketts and Kirshbaum.³⁶

Participants. The Delphi survey designed in Part 1 was distributed to a convenience sample of 60 students and 60 academics from the four universities and 30 service users and carers who had completed the PLJ workshops but who were not in the ALGs.

Data collection. The questionnaires were administered in person to students currently studying on health and social care courses and the staff teaching them across the four universities. The student and staff groups involved in the process were either studying or teaching within one of the sixteen disciplines engaged in the ALPS as shown below:

Audiology	Operating department practitioner
Clinical psychology	Optometry
Dentistry	Pharmacy
Dietetics	Physiotherapy
Medicine	Podiatry
Midwifery	Radiography
Nursing, (adult, child, learning disability and mental health)	Speech and language therapy
Occupational therapy	Social work

Thirty questionnaires were sent out to service users giving a total of 150 questionnaires.

The analysis of the questionnaires, including free comments, was conducted by the part 2 lead and discussed with the project team. Descriptive statistics and graphing of the quantitative data was used to identify ranking and degree of consensus within and across the groups. Qualitative statements were tabulated to identify concurrence or further themes. Findings from the questionnaire were then discussed at a meeting with members of the ALGs with the project team, where the project as a whole was reviewed (See Fig. 2 for an overview of the process).

The continual attention to rigorous, iterative involvement of users and carers, as well as the academic team, was important for effective and ethical action research.

Findings part 2. The response rates for each group are summarized below:

	No. questionnaires distributed	No. questionnaires returned	
	Number	Number	%
Student group	60	24	40
Staff group	60	31	51
User and carer group	30	22	73
Total	150	77	52

Not all questions were answered by all respondents.

Analysis of the survey data indicates that there is general agreement on what is most

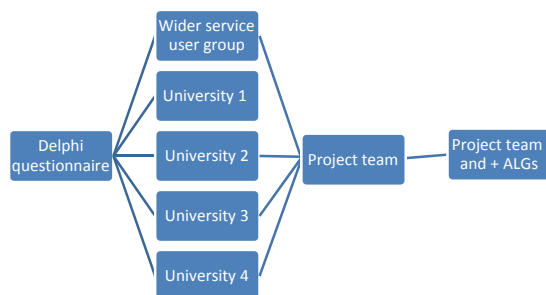


Figure 2 Overview of the Modified Delphi Process. Flow chart demonstrating the modified Delphi Process. ALG, Action Learning Group.

important for service users and carers when using health and social care services across all three survey groups. When asked to rank in order of importance the following – avoiding jargon; being flexible; being honest; being up to date; down to earth and listening – there was agreement about the top three.

The rank orders of attributes by survey group.

	Service users <i>n</i> = 21, %		Students <i>n</i> = 22, %		Staff <i>n</i> = 30, %
Being honest	24	Listening	25.5	Being honest	24.5
Listening	23	Being honest	23	Listening	23
Being up to date	16	Being up to date	16	Being up to date	19.5
Down to earth	14	Avoiding jargon	13	Being flexible	13
Being flexible	13	Down to earth	12	Avoiding jargon	10
Avoiding jargon	10	Being flexible	10.5	Down to earth	10

Although in the same position, being up to date was scored higher by academic staff possibly reflecting the focus of their work. Students' ranked avoiding jargon higher and being flexible lower than both other survey groups. This may reflect the students' own difficulty with jargon and being able to work flexibly owing to less experience of the service. This difference was also reflected in a later question, '*It is important for professionals to behave in a way that marks them out as different from patients/service users and carers*' the student survey group were 50% more likely than the staff or service user/carers to answer 'yes'. It is postulated that this is because students are beginning to develop a professional identity as part of their training and they feel the need to protect this identity to become 'professionals'.

There was also general agreement when asked to rank order the following behaviours, showing respect, sharing power, being open and honest, giving time and being self-aware.

The rank order of behaviours by survey group;

	Service Users <i>n</i> = 21, %		Students <i>n</i> = 22, %		Staff <i>n</i> = 31, %
Showing respect	26	Showing respect	27	Showing respect	27
Giving time	22.5	Giving time	24	Being open and honest	21
Being open and honest	22.5	Being open and honest	23	Giving time	19
Sharing power	16	Being self-aware	13.5	Being self-aware	18
Being self-aware	13	Sharing power	12	Sharing power	15

As with the rank ordering of the identified attributes, the lower scores were also of interest and perhaps indicative of the students' lack of confidence as they considered sharing power to be least important.

The remaining questions were of the agree/disagree format and the following have been selected as examples. The two graphs below show the questions with the greatest concurrence of opinion (question 6) and the greatest diversity of opinion (question 5) (Figs 3 and 4).

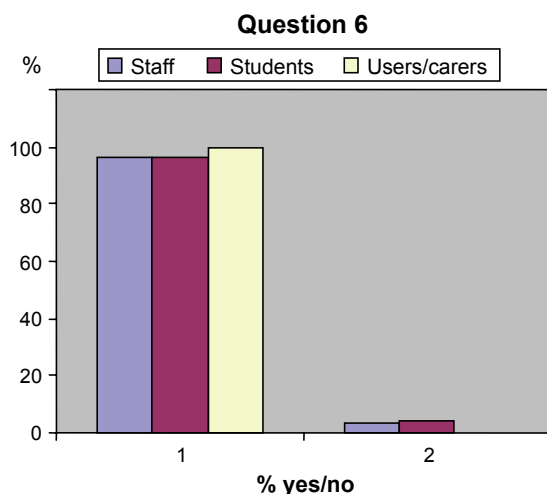


Figure 3 Professionals should check if a person can or cannot understand what is being discussed: (1 = yes, 2 = no).

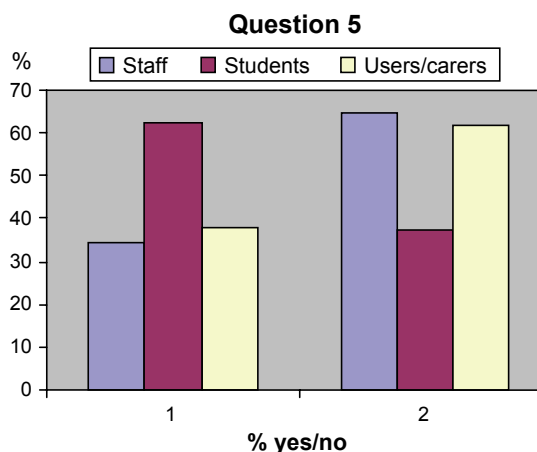


Figure 4 It is important for professionals to behave in a way that marks them out as different from patients/service users and carers: (1 = yes, 2 = no).

Discussion and implications

Whilst the Delphi confirmed that the views of the original workshop groups were more widely held, what became apparent from free text annotations on the questionnaires (these are not included owing to the confines of this article) and from discussions was that the rich meaning of the original ALG discussions became 'lost', once it was reduced to a single question and removed from the original context. This has been considered to be one of the main disadvantages of using the Delphi approach:

Just as a linear progression of words fails to communicate a Rembrandt painting, so a panellist may be unable to communicate his views or insights by means of a concise sentence or even by diagrams.. (Turoff and Linstone (1979), pp. 565)³⁵

This is not to say that the content of the questionnaire and results are not useful but the project group consider that to use them for the design of an assessment tool has limitations. It would be better to use the information to facilitate and support guided reflective learning and discussion during which wider contextual issues can be explored. This along with other work^{2,4,5,7} suggests that more work needs to be undertaken in relation to both the design and conduct of student assessments by service users.

As with other studies^{3,9,8} important learning from the project was that of the participants:

both professionals and users reported significant personal development and increased capacity for partnership. The following are examples of comments which occurred as a result of reflecting on the project during the writing of this article;

'I started this journey about 3 years ago from then on I've been involved in numerous projects. It has opened many doors for me as a service user and carer, the one that stands out for me is I'm definitely more confident. I soon realised that I was an expert by experience. Service user and carer journeys are long and difficult, usually an up-hill struggle to get the medical professionals to listen and take on board our experience and wealth of knowledge. Working on different projects with students especially the ALPS What Matters to Users of Services project I now have the courage, confidence and capability to stand my ground and be heard without getting angry and upset. I describe my long term disability and caring role as a bag of jumbled jigsaw pieces – I have no picture to look at but I know what I need. The first corner piece of the jigsaw was doing the PLJ; I started to join the pieces when I got involved in the ALG. It matters to the group how we are cared for, treated and listened to – getting these things makes life so much easier and so adds more pieces of the jigsaw. I may not be a medical expert but I know what works for me and I'm willing to listen and compromise – the picture is beginning to appear. I doubt my jigsaw will ever be complete but I hope it will help the students to see the bigger picture'.

'Being on the PLJ has really helped me to view my health in a different way, I have to take responsibility so now I ask the GP 'How can I help you to help me today Dr?'

'I really didn't think I had anything to offer but going through the Patient Learning Journey and being part of the Action Learning Groups made me realise that I'm an expert by experience and I can help other people to learn about living with my condition'

'Being given permission to tell my story was so therapeutic, the other patients and carers in the group had different conditions but we could identify common themes and these helped us to bond and support each other. When times are good or even hard we can and do support each other'.

'I've really enjoyed being involved because I'm learning too and if one person makes a change because of my experience then that's a bonus'.

From this a collaborative network of service users, carers and educators has emerged where further development of learning and assessment tools could take place.

Limitations

The research was carried out by advocates of service user and carer involvement which may have resulted in bias. The researchers were, however, overtly part of the research process, as is acceptable in studies such as this and contributed to the data in a reflexive manner. It should also be noted that the service users and carers involved in the project had previously been through PLJs and therefore may not represent service users as a whole. This may have influenced their responses to some of the questions, for example, the relatively low score they gave to avoiding the use of jargon.

In terms of rigour, it would be possible to replicate both ALG format and/or the survey element of the study.

Conclusions

Taking the results from the two rank order questions identifies there was agreement that the following attributes and behaviours of professional health and social care workers are important in helping service users and carers to contribute to their own care; being open and honest; showing respect; listening; giving time and being up to date. These have similarities to the categories as identified as important for mental health nursing students.² It may be that the qualities considered as important for shared decision making are the same as those valued generally by service users.

We utilized useful methods for involving users and carers as co-producers in assessment, as well as reference and work groups to support further development with user/carer perspectives. Service users and carers have been able to use a collaborative forum to provide information to influence and shape assessment practice and several of them

reported that their capacities and confidence have been greatly enhanced. The participative aspects of the project helped us realize the fuller potential of the contribution of the users and carers. We are keen to extend and refine these participative processes. We also understand more about the 'use of self' and the validity and place of personal experience in research activity, discovered through our shared, reflective process.

Re-useable learning objects are being produced with the aim of developing insight into the communication process from the service user and carer perspective. The aim of these materials is to enhance student learning.

Learning from the project in relation to both the findings and the conduct has been cascaded in each of the Universities involved.

Service users and carers are too often a missing expertise in the development of professional curricula. It is possible to involve them ethically and effectively, but this requires a similar reflective engagement by the professionals involved.

The project team was established, with largely the same membership as the earlier project on developing PLJs from which the original ALPS collaboration grew. This continued hard-won collaborative practices and good relationships across the four universities. It also meant that the group memory of how to achieve real, not token, co-working informed and deepened the participative research with users and carers. It is important to note that three members of the project group were designated user/carer workers and all members were comfortable to bring their patient/carer/user selves to the table, thus ensuring a consistent user voice throughout the research process. Research leadership across the two methodologies and effective project management were enhanced by the longstanding nature of this group, which took place over a number of years.

Given the potential of involving users and carers in professional learning, we need to build this into our curriculum development processes. Given also its value to all concerned, it is worth applying this principle seriously.

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Conflict of interests

No conflicts of Interest are declared.

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